

Secretary's Advisory Committee on Genetic Testing

Secretary of Health and Human Services Donna Shalala chartered the Secretary's Advisory Committee on Genetic Testing (SACGT) in June 1998 in response to recommendations of two working groups commissioned jointly by the National Institutes of Health (NIH) and the Department of Energy (DOE) for the Human Genome Project. The groups were the Task Force on Genetic Testing and the JointNIH/DOE Committee to Evaluate the Ethical, Legal, and Social Implications Program of the Human Genome Project. These groups identified the need for broad-based public policy development to help the Nation address the benefits and challenges of genetic knowledge and genetic testing. The Secretary assigned the management of theSACGT to the Director, NIH. The SACGT will advise the government about all aspects of the development and use of genetic tests, including the complex medical, ethical, legal, and social issues raised by genetic testing. Among the general issues that the Committee may take up include: the development of guidelines, including criteria regarding the risks and benefits of genetic testing, to assist Institutional Review Boards in reviewing genetic testing protocols in both academic and commercial settings; the adequacy of regulatory oversight of genetic tests; provisions for assuring the quality of genetic testing laboratories; the need for mechanisms to track the introduction of genetic tests to enable accuracy and clinical effectiveness over time to be evaluated; and safeguarding the privacy and confidentiality of genetic information and preventing discrimination and stigmatization based on genetic information. Procedurally, recommendations made by the Committee will be submitted to the Secretary through the Assistant Secretary for Health.